

III. Partnering with Families and Youth

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How to Use This Section

In this section, you will find guidance to support a key building block of quality care and system of care and that is respectful partnerships with families and youth. Each section contains guidance and tools to assist you. If you are in the very beginning stages of involving families and youth in Collaborative meetings, other meetings, and policy, program or organization development, it is recommended that you review the sections from the beginning. If you are further along with family involvement, then it is recommended that you review each question and review materials under the one that best supports the stage of development you may be experiencing. The section on evaluating your progress in partnering with families and youth will help you in determining where to start.

Under most questions you will also find useful “**TOOLS**” to assist you in that particular area of family and youth collaboration. Each of these tools will have a link with the title as well as a brief summary of its use. The **TOOLS** section may also include other helpful links, websites or articles.

What Defines Respectful Partnerships with Family and Youth and Why Do It?

While the specifics may vary, family-centered or family driven care is rapidly becoming accepted as best practice whether in health care, education, mental health, substance abuse or other service arenas. Whatever the definition, they all include the fundamental principle of respectful partnership. Listed below are several definitions of family-centered or family driven care that help to illustrate the richness of these partnerships.

Family-Driven Care

(Federation of Families for Children’s Mental Health; <http://www.ffcmh.org>)

Family-driven means families have a primary decision making role in the care of their own children as well as the policies and procedures governing care for all children in their community, state, tribe, territory and nation. This includes:

- Choosing supports, services, and providers;
- Setting goals;
- Designing and implementing programs;
- Monitoring outcomes;
- Partnering in funding decisions; and
- Determining the effectiveness of all efforts to promote the mental health and well being of children and youth.

Guiding Principles of Family-Driven Care

1. Families and youth are given accurate, understandable, and complete information necessary to set goals and to make choices for improved planning for individual children and their families.
2. Families and youth, providers and administrators embrace the concept of sharing decision-making and responsibility for outcomes with providers.
3. Families and youth are organized to collectively use their knowledge and skills as a force for systems transformation.
4. Families and family-run organizations engage in peer support activities to reduce isolation, gather and disseminate accurate information, and strengthen the family voice.
5. Families and family-run organizations provide direction for decisions that impact funding for services, treatments, and supports.
6. Providers take the initiative to change practice from provider-driven to family-driven.
7. Administrators allocate staff, training, support and resources to make family-driven practice work at the point where services and supports are delivered to children, youth, and families.
8. Community attitude change efforts focus on removing barriers and discrimination created by stigma.
9. Communities embrace, value, and celebrate the diverse cultures of their children, youth, and families.

10. Everyone who connects with children, youth, and families continually advances their own cultural and linguistic responsiveness as the population served changes.

Characteristics of Family-Driven Care

1. Family and youth experiences, their visions and goals, their perceptions of strengths and needs, and their guidance about what will make them comfortable steer decision making about all aspects of service and system design, operation, and evaluation.
2. Family-run organizations receive resources and funds to support and sustain the infrastructure that is essential to insure an independent family voice in their communities, states, tribes, territories, and the nation.
3. Meetings and service provision happen in culturally and linguistically competent environments where family and youth voices are heard and valued, everyone is respected and trusted, and it is safe for everyone to speak honestly.
4. Administrators and staff actively demonstrate their partnerships with all families and youth by sharing power, resources, authority, responsibility, and control with them.
5. Families and youth have access to useful, usable, and understandable information and data, as well as sound professional expertise so they have good information to make decisions.
6. Funding mechanisms allow families and youth to have choices.
7. All children, youth, and families have a biological, adoptive, foster, or surrogate family voice advocating on their behalf.

Patient- and Family-Centered Health Care

(Institute for Family-Centered Care; <http://www.familycenteredcare.org>)

Patient- and family-centered care is an innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care patients, families, and providers. Patient- and family-centered care applies to patients of all ages, and it may be practiced in any health care setting.

What are the core concepts of patient- and family-centered care?

- **Dignity and Respect.** Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.
- **Information Sharing.** Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful.

- **Participation.** Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.
- **Collaboration.** Patients and families are also included on an institution-wide basis. Health care leaders collaborate with patients and families in policy and program development, implementation, and evaluation; in health care facility design; and in professional education, as well as in the delivery of care.

Family-Centered Care

(Maternal & Child Health Bureau, Division of Services for Children with Special Health Needs)

Family-Centered Care assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-Centered Care is the standard of practice that results in high quality services.

Principles of Family-Centered Care for Children

The foundation of family-centered care is the partnership between families and professionals. Key to this partnership are the following principles:

- Families and professionals work together in the best interest of the child and the family. As the child grows, s/he assumes a partnership role.
- Everyone respects the skills and expertise brought to the relationship.
- Trust is acknowledged as fundamental.
- Communication and information sharing are open and objective.
- Participants make decisions together.
- There is a willingness to negotiate.

Based on this partnership, family-centered care:

1. Acknowledges the family as the constant in a child's life.
2. Builds on family strengths.
3. Supports the child in learning about and participating in his/her care and decision-making.
4. Honors cultural diversity and family traditions.
5. Recognizes the importance of community-based services.
6. Promotes an individual and developmental approach.
7. Encourages family-to-family and peer support.
8. Supports youth as they transition to adulthood.
9. Develops policies, practices, and systems that are family-friendly and family-centered in all settings.
10. Celebrates successes.

These varied definitions reflect the varied ways in which professionals along with families and youth must collaborate when implementing Systems of Care. The voice of those we serve is the voice that will improve the system. However, the system has to create avenues and ways to partner with families in a valuable way before that begins to happen.

TOOLS

Websites:

There are a number of organizations that have guidance materials and provide training and technical assistance on family-centered, family-driven care. While some of these organizations may focus on children with chronic illness or developmental disabilities, the resources and technical assistance available are applicable to children and families with mental health and/or substance use challenges.

North Carolina Families United

Powerful Youth Friends United

<http://www.ncfamiliesunited.org>

Federation of Families for Children's Mental Health

<http://www.ffcmh.org>

Institute for Family-Centered Care

<http://www.familycenteredcare.org>

Parent to Parent USA

<http://www.p2pusa.org>

The Beach Center on Families and Disability at The University of Kansas

www.beachcenter.org

Family Voices

www.familyvoices.org

National Fathers Network

www.fathersnetwork.org

Research and Training Center on Family Support and Children's Mental Health

Portland State University

<http://www.rtc.pdx.edu/>

Why Partner with Families and Youth?

This question can probably be answered best by a quote from Claire Forest, Director of Cornell University's Family Development Credential:

“Within each person lies a bone-deep longing for freedom, self-respect, hope and the chance to make an important contribution to one’s family, community and the world. Without healthy outlets for this powerful, natural longing, the desire for freedom turns into lawlessness, and the need for self-respect is expressed in aggression and violence. Without avenues to make important contributions to family, community and the world, hopelessness translates into dependency, depression, violence, substance abuse and other forms of self-abuse. No government program can help families become self-reliant, contributing members of their communities unless it is built on a recognition of the power of this bone-deep longing for freedom, self-respect, hope, and the chance to make an important contribution.” (Dean, 1996; updated, Forest, 2003)

Not only should families be involved but families need to be involved. Much of a family's life is driven by the needs of the children. When children in a family are not doing well, the whole family is impacted. Often it is difficult to discern which comes first...the child experiencing problems that changes the dynamics of the family or the family experiencing challenges that changes the dynamics of the child. What we do know is that people that feel in control of their lives are happier people and have more success. Families need to be in control of decisions that impact their lives. Gone are the days of plans being done for people. Best practice demands that people drive their own care and as a result, their own lives. Children get better when their families are involved in their care. This is beginning to be acknowledged from every child serving agency. If they are satisfied consumers, families are the best advocates a public agency can have. When families participate in their child's care, it increases their knowledge of the challenges involved with living with a mental illness, opens doors to information about skills they can develop to cope with the challenges, offers opportunities to build resiliency in self and family while providing hope for positive outcomes.

How Do We Assess the Current Level of Family/Youth Involvement?

Family/youth involvement is one of the key elements to SOC implementation. Without family voices, input and guidance, our systems continue to create a new design with the same approaches. However, family involvement ensures that decisions are based on what families say they want and need, rather than what systems think they need. Knowing exactly how involved families and youth are from the beginning will inform where you should begin your SOC implementation planning. One key to involvement is assessing your community's current

level of family/youth involvement. Therefore, although you may not have families or youth involved in your particular agency or Collaborative, it does not mean they are not involved in other areas within the larger community or service system. You can begin where there is already success and documenting those successes and challenges will help you learn where to start.

Asking some basic questions also may be helpful in determining the current level of family or youth involvement:

- Are parents, family members and/or youth involved in every initiative, meeting, or discussion from the beginning?
- Is there an organized orientation of family members coming to the table (i.e., orientation for collaborative involvement, review of committee or meeting purpose in advance, Roberts Rules of Order, etc.)?
- Is there a way to provide financial reimbursement for time and travel?
- Does the agency embrace a “Nothing about a family without a family present” philosophy? For example, do Child and Family Team meetings, committee meetings, task forces, etc. continue if a parent or family member is not there?
- Are family satisfaction surveys conducted regularly and are the data compiled and used to engage and involve families in determining system change?
- Does the agency have a family and youth involvement recruitment plan?
- Has the agency created a comfortable environment for engaging and involving family and youth?
- Has the agency created flexibility around when, where and how long to meet to increase the opportunities for families and youth to attend?
- Has the agency thought about all the different ways in which families and youth can be partners?

TOOLS

Family Involvement Self-Assessment (Family Resource Coalition of America)
This particular tool is helpful in assessing the quality and nature of family involvement in your collaborative or initiative.

Family Driven – Youth Directed Services Checklist: This tool can be used to evaluate systems for family driven – youth directed care. Providers and families should use this document as a learning tool and make revisions to fit the needs of the child and family.

Family Partnership Continuum: (Adapted from materials developed by the National Peer Technical Assistance Team, originally conceptualized by Keys for Networking, Jane Adams, Director) This document shows the progression from professional driven to family driven services.

Family Professional Partnership - A Continuum Toward Collaboration: This document shows the difference and similarities between conventional, cooperative and collaborative systems and allows the viewer to identify the process they may be using.

Questions to Assess Family Involvement in System Design and Development: (Pat Solomon and Libby Jones) These guidelines can be used to help agencies to incorporate family involvement in their agency. It can be used as a checklist to see if they are practicing family driven care.

Where Do We Need to Partner with Families and Youth?

Families should be involved at every level. Consider how it might feel to have someone make decisions for you, about you, without you. That is what the system tends to do, with the best of intentions, on a regular basis. So in order to involve families, we must look at every level: Child and Family Teams, policy and decision making level, advocacy, research, Family Organization development and anywhere else we may think is important. The best way to know the areas that are important to families is to ask them.

TOOLS

Position Descriptions: As agencies move toward formalized partnerships with youth and families, they often think about paid positions within their organizations. The Institute for Family-Centered Care has posted several paid parent positions that exist in health care arenas. These can be downloaded for free at:

<http://www.familycenteredcare.org/tools/position.html>

Family Leadership in Policy, Evaluation, and System of Care: The Federation of Families has a number of resources on how to partner with families in policy, evaluation and in system of care. Of particular interest is the work on partnering with families in research and program evaluation which is often overlooked when professionals think about family/youth/professional partnerships. These resources can be found at the Federation's website: <http://www.ffcmh.org/index.htm>

How Do We Get Families to the Table?

If we treat families with respect, show that their input is truly needed, use that input so that the impact of their input is evident, and support them so that they can be in a place where they can partner with professionals in a variety of ways, they will come.

But the bottom line comes down to what the system *does* to support their intentions. As professionals, each person is paid for their time in meetings, reimbursed mileage and sent to conferences and training to continue his/her learning. Yet we often ask families to participate on committees, meetings and advocate without the same supports in place. So we must start putting money on the table. When we show parents in tangible ways their "worth" by paying for their expertise just as professionals are paid, we remove a major barrier to partnerships.

There are several things to consider when recruiting parents and youth to come to the table:

- Does the parent/family member have interest in participating? Have we provided an environment where families can say no? Sometimes we pressure families to participate when we see the talent and potential, but they may have a hard time telling us “no – not my interest or not at this time”
- Does the parent/family member have the time to commit – even if there is flexible scheduling? Some families are too involved with their children or family member at the time we are asking them to participate.
- Does the parent/family member have experience with the specific issues that brought the group together? For example, a committee may be looking at access to the system for children with mental illness, so a parent, youth or family member who had experience with that is critical. Sometimes it is easier to call on a parent we know, but they may not possess the experience needed for that group or task.

These basic questions can impact our ability to properly match family involvement with the tasks. We do not want to pressure families into a role they are not comfortable with or interested in and we do not want to “meet” criteria by bringing just any family member.

Keep in mind that flex funds need to be just that – flexible. Get creative when creating a flex fund pool of money. Consider the following when finalizing your own community’s protocol:

- Use funds to cover creative or non-fundable activities that support creative planning at the Child and Family Team table.
- Create small “pots” of money that the Child and Family Team can access easily to support plans.
- Use funds only to mobilize informal/community supports
- Use funds for supplies and materials needed to support a family (Example: one CFT strategy included a family coming together around the table when they began to escalate. The family created a signal that meant they all go to the table and begin their process to diffuse the situation. However, this family did not have a table to sit around. Flex funds bought the table.)

So how do we pay them for their time? Well you might need to get creative or get collaborative! Below are several possibilities for funding family involvement activities:

- Pool local dollars from each agency to create a flex fund and stipend fund.
- Use their Non-UCR dollars to support family involvement as agreed upon by the Collaborative.
- Apply for grants and incorporate family participation and those costs associated with that activity.
- Prioritize local county dollars to support these activities.
- Fund raise in the community.

TOOLS

Flex Funds Protocol and Form (example): This document can serve as an example of how to create a flex fund process. This document can be revised to meet your community's needs.

Stipends Protocol and Form (example): If we ask families to the table to give us their input where committees, task forces and policy development are concerned then we should reimburse them. If we ask them to gain skills by participating in conferences and training, they should be reimbursed. The following protocol and form is an example of how stipends are accessed for families. This document can be revised to meet your community's needs.

Building Partnerships (by Pat Solomon): This document can be used to facilitate discussions around community partners, relationship building and why there should be partnerships.

Inviting Families to the Table (Party): (Pat Solomon and Libby Jones)
This document parallels how inviting families to the table is similar to inviting people to a party. The document includes a list of details to consider when inviting families to join collaborative work with agencies.

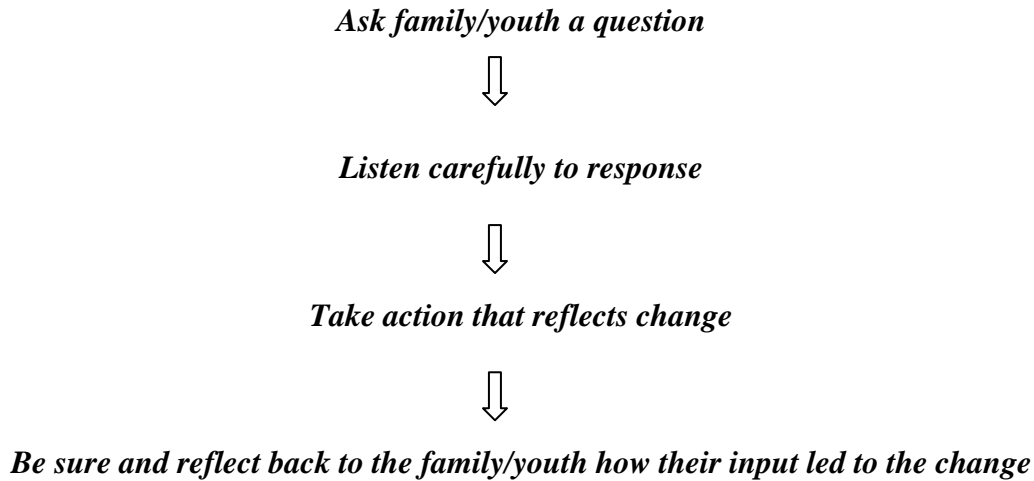
How Do We Know When We Have Families and Youth Truly Involved?

You will know when families and youth are truly involved by observing the following:

- Parents/family members/youth are coming to the table.
- Parents/family members/youth openly give feedback and share honest opinions.
- Parents/family members/youth tell us they see a difference.
- Satisfaction surveys indicate true partnerships.
- Observational probes reflect tangible indicators of partnerships and creative solutions to the barriers to involvement.

Finally, if we really want to know if families are truly involved, ask them. They will tell you and if we listen, they will let us know more and more often what their thoughts and ideas are. However, most importantly, until we stop making excuses for our policies or spend time convincing families why we do what we are doing, we will never have true family or youth involvement.

There is a simple formula for true involvement:



As we involve families in informing us how to adjust and change the system , we must continuously revisit our questions and reviewing where we fall on the Family Professional Partnership continuum.

TOOLS

Family Professional Partnership - A Continuum Toward Collaboration:

This document shows the difference and similarities between conventional, cooperative and collaborative systems and allows the viewer to identify the process they may be using.

Why Develop Family Advocacy Organizations in Our Community?

There are so many benefits to family advocacy organizations being developed in the community. The benefits include:

- Often Family Organizations can get family members to the table when agency staff cannot. Advocates, as defined in the previous section, can prepare families for meetings, assist in conveying their concerns, serve as a liaison between family and team members, help tap into informal supports of the family, but most often, can serve as the first trusted member of the team. When team meetings occur, the family “Stuff” is open to everyone, but no one else’s “stuff” is. It is a very intimidating process for someone new to the group. And if the family member has not had success with the system, they do not want to subject themselves to that again. Advocates can be a huge support to begin the planning process. So when a family does not come to a meeting, maybe it is not because they are “out of compliance” but because they lack trust or confidence to participate in the planning process.

As mentioned above, the same funding sources and approaches can be tapped into to support the development of family organizations. How do we pay them for their time? Well you might need to get creative or get collaborative! Below are several possibilities for funding family involvement activities:

- Pool local dollars from each agency to create a flex fund and stipend fund.
- Use Non-UCR dollars to support family involvement as agreed upon by the Collaborative
- Apply for grants and incorporate family participation and those costs associated with that activity.
- Prioritize local county dollars to support these activities.
- Fund raise in the community.

TOOLS

Draft Guiding Principles for Cultural and Linguistic Competency in Family Organizations:

This document can be used as a guide in developing cultural competency in a family organization.

Family Organization Planning Format: This format can be used to guide organizational plan development with groups. It provides a progressive layout for thinking through the steps to setting goals and creating action plans.

Family Organization Stakeholder Survey:

This survey is a tool to illicit feedback from members in a family organization. It looks at the strengths and challenges for the organization. It could be used to help develop a strategic plan or logic model.

Sample MOA between Families and Agencies: This document a tool to use when engaging with a family to provide System of Care services and Family Advocacy and Support services. Tool is set up as an agreement signed by both parties, which explains the services offered, by both the service provider and the Family Partners, outlining what the family can expect upon agreement with utilizing System of Care services and supports.

Technical Assistance Plan Form (from UACC): This is an example of a Technical Assistance plan to help develop a non-profit organization for families. It can be a useful guide for assessing the strengths and needs of an organization.

How Can Families Support Practice Change?

When family voices are united and organizations are created for family advocacy, numerous supports to the system can be created:

- Families can advocate for things at the legislative level that agency staff cannot.
- Family organizations with advocacy roles can support the Child and Family Team process.
- Families can assist in getting more families involved – “Reach one Teach one” approach.
- Feedback and satisfaction surveys can inform us of how we are doing with change.
- Most grants now require collaboration with families and family involvement at all levels. The more we partner with families, the better our grant applications become.
- Family members can become trainers and begin getting more parents involved in training. The parent voice in teaching and training will bring about practice change from their perspective. Employees of an agency, unless also a parent of a child served in the system, cannot convey that message through training.

TOOLS

Child and Family Team: An Interview with a Parent: This interview template may be useful for gathering family satisfaction feedback specific to the CFT planning process.

Involving Families in Policy Work: (Federation of Families for Children’s Mental Health)

This Tip Sheet offers guidance for involving family members in the work of mental health policy groups. It provides a definition of “family member” and briefly describes the context for family involvement in policy group work. It contains strategies for recruiting family members to join policy groups, training and supporting family members to do the work, and sustaining their participation over time.

Helpful Links and Articles

Websites:

www.ncfamiliesunited.org

North Carolina Families United revised the System of Care Handbook for Families. This was an effort to help families navigate the systems and help empower families. It has samples of how to write letters and information on the importance of documentation.

www.ffcmh.org

The Federation of Families for Children's Mental Health is a nation family-run that serves to:

- Provide advocacy at the national level for the rights of children and youth with emotional, behavioral and mental health challenges and their families
- Provide leadership and technical assistance to a nation-wide network of family run organizations
- Collaborate with family run and other child serving organizations to transform mental health care in America

www.tapartnership.org/youth/youthguide.asp

The goal for *Youth Involvement in Systems of Care: A Guide to Empowerment* is to provide a resource to youth, youth coordinators, family members, professionals, and other adults working with young people. This guide is a starting point for understanding youth involvement and engagement in order to develop and fully integrate a youth-directed movement within local systems of care.

The mission of *Youth Involvement in Systems of Care: A Guide to Empowerment* is to educate all professionals and adults who work with young people on the importance of engaging and empowering youth. This guide will serve in building the foundation and framework for the Youth Movement in order to enhance opportunities for young people and to utilize their expertise in system change.

<http://rtckids.fmhi.usf.edu/rtpubs/familyexperience.htm> or <http://pubs.fmhi.usf.edu>

The Family Experience of the Mental Health System Study was designed to meet the need from family perspectives about service access and delivery, as well as, specific aspects of services that are most and least helpful. Over a two-year period, families shared their experiences as they sought treatment, remained in treatment or terminated treatment.

A Findings Compendium was developed, along with the following checklists, which summarize findings and their policies and practice implications. Based on the experiences of the families in the study, as well as evidence-based and promising practices, these checklists can help guide the development of systems of care as they address child and family issues of: Medication, Decisions and Responsibilities of Care, Pathways and Access to Care and, Helpfulness of formal organizations and informal Supports.

This publication is available on-line as an Adobe Acrobat PDF file:

Developed by:

The Research and Training Center (RTC) for Children's Mental Health

Department of Child and Family Studies,

The Luis de la Parte Florida Mental Health institute (FMHI)

At the University of South Florida, Tampa, funded by the National Institute on Disability and rehabilitation Research

<http://www.ffcmh.org/publications.htm> (Federation for Families website)

Bringing Families to the Table

www.ovid.com/site/catalog/journals_landing.jsp (to get a copy of the article)

-Briggs, H.E., & Koroloff, N.M. (1995). Enhancing family advocacy network: An analysis of the roles of sponsoring organizations. *Community Mental Health Journal*, 31 (4), 317-333.

The common roles and responsibilities assumed by sponsoring organizations with regard to family advocacy networks for children's mental health was derived from a 3 year study which observed the relationship between 7 sponsoring organizations and family advocacy groups. A conceptual framework is proposed to define these roles. Advantages, limitations, and critical issues of each of these roles are discussed.

-Federation of Families for Children's Mental Health. (1998, Summer). Making Family Participation in Research and Evaluation a Priority. *Claiming Children*. (pp. 1-16). Alexandria, Va.: Author.

www.ffcmh.org/pub_children.htm

This special issue addresses the need for family participation in research and evaluation. It specifies why family members should be interested in research and evaluation, what it takes for family members to use research, and attempts to clarify for families the language used by researchers to communicate their findings. A description of a project evaluation in which parents contributed is also presented.

www.rtc.pdx.edu/pgPublications.php

-Friesen, B.J. & Osher, T.W. (1996). Involving families in change: Challenges and opportunities. *Special Services in the Schools*, 11 (1/2), 187-207.

This article discusses a range of matters related to the involvement of families with children with severe behavioral and emotional disorders. Family participation on education and system change is reviewed and principles of family participation is discussed.

www.fpg.unc.edu/~SCPP/rguide/pages/resource_list.cfm

-Jeppson, E., Thomas, J, Markward, A., Kelly, J., Koser, G., & Diehl, D. (1997). Making room at the table: Fostering family involvement in the planning and governance of formal support systems. Chicago, IL: Family Resource Coalition of America.

This guide seeks to help professionals enhance family involvement in formal systems of service and support. An entire day agenda is described and details about how to employ several topics and issues is provided. Examples of some topics discussed include: identifying the benefits and barriers of family involvement, defining the family and family involvement, and developing plans of action for their own family involvement.

www.tacenter.net/statewide/statewide.cfm?state=MS

-Schweitzer, T.B. & Hankins, B.J. (1997) Families as allies: A series of workshops for families whose children are experiencing serious emotional & behavioral disorders. Raleigh, NC: Families Children and Adolescents Network.

This document is a comprehensive training program of family involvement. It is an excellent opportunity for families and professionals to work together to develop a plan for establishing support for families of these children. Sessions focus on strategies for coping, behavioral management techniques, assertiveness training, parent/professional collaboration. Information about systems of care, emotional & behavioral disturbances, and treatment strategies.

www.rtc.pdx.edu/pgFP504TOC.php

-Friesen, B. (Summer 2004) Family participation in out-of-home treatment settings: Challenges and opportunities.

This article reports on research focusing on family members' experiences when their children are in out-of-home care. Findings point to areas where the practice, programs, and policies of out-of-home services can be improved.

www.rtc.pdx.edu/pgFocalPoint.shtml

-Caplan, E., Blankenship, K., McManus, M. (Fall 1998) Focal Point: A National Bulletin on Family Support and Children's Mental Health: Family Participation in Policymaking.

This issue focuses on how families can participate in policymaking and what supports are needed for them to participate.

Building Family Advocacy

http://gucchd.georgetown.edu/object_view.html?objectID=2553

-Donner, R., & Fine, G.Z. (1987). A guide for developing self-help/advocacy groups for parents of children with serious emotional problems. Washington, DC: Georgetown University Child Development Center.

This workbook serves as a guide for the creation of self-help/advocacy groups for parents of children and adolescents who have serious emotional problems. An explanation for the need for self-help/advocacy groups, a description of who qualifies as a seriously disturbed child, and steps to get the groups started are provided. Several examples are included at the end of the workbook in order to assist the future self-help/advocacy group developer.

www.ct.gov/opapd/lib/opapd/documents/adobe/organizing_parents_manual.pdf

-State of Connecticut Office of Protection and Advocacy for Persons with Disabilities. Organizing Parents: Building Family Advocacy Organizations.

This manual gives practical strategies for organizing a grassroots parent organization. The strategies include how to support parents, making systems change and organizational governance.

www.rtc.pdx.edu/pgFeaturedDiscussions18A.php

-Family involvement and the older adolescent: Where does advocacy stop and interference begin. (Discussion).

www.state.ia.us/earlychildhood/docs/PartIREVISED.pdf

-State of Iowa Early Childhood Division: What is Advocacy?

This article provides a simple definition of what advocacy is and who advocates are. Clear and simple ways to advocate are listed with ways to implement.

Articles:

A Call for SOC: (NC Families United, FFCMH)

NC Families United FFMCH, a statewide family organization, developed this white paper. It emphasizes the importance a coordinated, seamless system of care that provides a safety network for families and children with emotional behavioral or mental health challenges.

Keeping the Promise for Families: A Discussion of Strategies and Tools for Safeguarding Statewide Family Networks: (Federation of Families)

This monograph is a discussion of strategies and tools for safeguarding statewide family networks.

Learning From Colleagues: Family/Professional Partnership - Moving Forward Together. (A Product of the Peer Technical Assistance Network)

The Peer Technical Assistance Network produced this document. It can be used to begin conversation about building a System of Care between families and services providers. The monograph uses research and commentaries to help guide the audience to understand how family / professional partnerships can help develop a System of Care for child who have or at risk of developing serious emotional disturbances.

NC Families United Risk Benefit Handbook: (NC Families United FFMCH)

This handbook is a comprehensive document for family organizations that specifies how an organization will protect the rights of the individual that participates in the organization. It offers examples of consent for participation in different kinds of events.

Parent Professional Collaboration in Children's Mental Health: The Role of the Family Advocate: (NC Families United, FFMCH)

NC Families United, a state wide family organization, developed this white paper. It highlights the special role that parents of children with emotional behavioral or mental health challenges should play in the design, development and implementation of a system of care.

SOC handbook: (NC Families United)

This handbook was revised by NC Families United FFCMH to help families' access appropriate services, understand what services should look like, and provides advocacy tools to help families

receive services. The handbook can be accessed by going to the NC Families United website at www.ncfamiliesunited.org.